

Working Group to Develop a State Plan for Alzheimer's Disease and Related Disorders

Care Delivery and Research Sub-Group

October 4, 2012

Run time: 9:21 to 10:00

RI Hospital: Aldrich Building 5th floor.

Present: Lindsay McAllister (Officer of Lt. Governor), Kathy Heren (Alliance for Better Long Term Care), Dr. Edward Stopa (RIH, Brown), Dr. Ana Fulton (Butler Hosp.), Dr. Peter Snyder (*chair*, Lifespan Hospitals, Brown)

Introduction:

1. The meeting began with introductions of everyone in attendance (listed above) and a brainstorm of other potential members of this working group.
 - a. Existing members: Dr. Patricia Gifford (also a member of the End of Life Committee), Dr. Brian Ott (Brown, RI Hospital), Anne Marie Caron (Evercare), Edward Quinlan (Hospital Assn. of RI),
 - b. Potential members the sub-committee would like to reach out to: Dr. Stephen Salloway (Brown, Butler), Dr. Geoffrey Tremont (Brown, RI Hospital), Dr. John Stoukides (Roger Williams), Dr. Paul Malloy (Brown, Butler), Dr. Susan Miller (Brown), Professor Catherine Graziano (*ret.* Salve Regina School of Nursing).

Agenda: Charge for Working Group

2. Peter Snyder discussed the need to focus on the intersection of *access* and *communication* for this working group because there are state-of-the-art research findings, but many physicians and primary care givers are not aware of them – and so these do not rapidly affect patient care. He stated that ethical, state-of-the-art practice includes access for patients to clinical research, and the committee should focus on designing improved bridges between the clinical research & practitioner communities across the state; as well as the need to better educate patients and their families/caregivers and to create better ways to involve them in statewide research efforts.
3. Ed Stopa suggested the creation of an online registry of AD patients and families; to allow them to both learn of new research results and identify opportunities to participate in clinical trials through local sites in R.I.
4. Peter Snyder noted that there is the beginnings of just such a registry that had been started at RIH (B. Ott & colleagues), and that this effort already includes active involvement of clinicians at Memorial Hospital; but a much larger network of clinical and research centers (especially Butler Hospital) must be actively engaged in this project for it to be effective and successful. This committee could champion and expand this nascent effort.
5. Ed Stopa also suggested the idea of implementing statewide dementia program in which dementia patients can be followed through their clinical care trials and can be assessed periodically. The program would be able to assess whether or not the drugs and treatment are working and it would have access to their tissues for research after they die, if patients are willing.

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6. Kathy Heren and Ana Fulton discussed the pressing need to better educate point-of-care clinicians about new developments in clinical and pre-clinical research in this field.
7. Peter Snyder brought up the idea of making the aforementioned website a portal for both patients and practitioners. The website could be a platform for all of the latest information and developments.
 - a. The state does not have funding set aside for this working group, but there is the potential to seek outside funding if this website were to be enacted. Also, this working group is attempting to outline actionable steps that the legislature could potentially act upon in the future.
 - b. Kathy Heren then added that there is a clear age and socioeconomic gap in technological proficiency. Many of the people she interacts with will not look at a website; they often take their doctor's word, which has the potential to be outdated.
 - c. There is currently a Geriatric Education Center at URI, which is supposed to bridge the gap between clinical and research care, but no one at the meeting was familiar with the specifics of their work. The center could be a potential key resource.
 - d. Ana Fulton noted that George Washington University holds the Geriatrics Education Center Consortium twice a year and could serve as a model for dissemination of research findings in Rhode Island.

Moving Forward

1. Peter Snyder will send out copies of NAPA and the Vermont Plan (sections that pertain to research) in word format so that we can edit, change and work with it as a starting point for next meeting. Perhaps NAPA could serve as a guide to an actionable state plan. At the next meeting, the working group will discuss relevant sections.
2. Ed Stopa brought up the possibility of reaching out to other state institutions such as Johnson and Wales University, Roger Williams University, and the state schools, as this is a statewide initiative.
3. Lindsay McAllister noted that there has been targeted outreach by the staff, but not to JWU specifically. Discussion was brought up about the self-selected nature of the working group and the possibility that no one in these institutions have their interests in this field. Regardless, Lindsay McAllister agreed it was a good suggestion and said she would work on reaching out to JWU and Salve Regina before the next meeting.
4. **The meeting adjourned. The next meeting will include a discussion and critique of the NAPA and VT plans.**